

# An Open Letter to the New Government

Improving lives of people living with rare conditions in the UK



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Wes Streeting  
Secretary of State for Health and Social Care  
The Department of Health and Social Care  
39 Victoria Street  
Westminster  
London  
SW10 0EU

Dear Minister,

I am writing on behalf of our Alliance of over 200 charities and support groups working together to improve the lives of people affected by genetic, rare and undiagnosed conditions.

Rare conditions are individually rare but collectively common, affecting over 3.5 million people in the UK. 1 in 17 people will be affected by a rare condition during their lifetime. These conditions can be both life-limiting and life-threatening.

People living with these conditions, and their families, face a lifetime of complex care:

- More than a third of people with a rare condition have to **wait more than five years** between first experiencing symptoms and receiving a final diagnosis
- More than **three out of 10 children** with a rare condition die before their fifth birthday
- Only **one out of 20 rare conditions** have an approved treatment or medicine to help people with rare conditions

Over the past few years we have begun to make progress through the 2021 UK Rare Diseases Framework which was co-signed by the health ministers of each nation, ensuring cross-border collaboration between each nation's civil service. The five-year Framework has been an effective vehicle to drive forward improvements for people with rare conditions, and facilitated the sharing of best practice across the devolved nations.

**We cannot afford to lose momentum, and our Alliance urges you to make a commitment to continuing the work of the UK Rare Diseases Framework.**

We want to work with you to set new ambitions that will:

- Help patients get a timely diagnosis
- Increase awareness among healthcare professionals
- Improve the coordination of care
- Increase access to specialised care, treatment and drugs.

Our '[Manifesto for Rare Diseases](#)' developed in collaboration with the Specialised Healthcare Alliance, outlines detailed recommendations to deliver on these ambitions.

Collectively, rare conditions pose a significant health challenge to the NHS, but they also present a valuable opportunity. Rare conditions will benefit from developments in AI driven diagnostics, genomic testing, cell and gene therapies, and digital care support. The combination of unmet need and the potential impact of innovation in the rare conditions space means that, with appropriate attention, rare conditions could help to fulfill the ambition for the Department of Health and Social Care to be a driver of economic growth for the UK.

Genuine partnership between the government, NHS, affected individuals, charities, and innovators has the potential to overcome the barriers that are holding back progress. Government support is required to set clear expectations, ensure that all parts of the system work together, and provide the resources needed to deliver change.

We are looking forward to working constructively together over the next five years to improve the lives of people with rare conditions across the UK.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Louise Fish', written in a cursive style.

Louise Fish  
Chief Executive  
Genetic Alliance UK

[A list of our member organisations](#)

Cc

Andrew Gwynne, Parliamentary Under-Secretary of State for Public Health and Prevention

Baroness Merron, Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health

Karin Smyth, Minister of State for Health (Secondary Care)

Stephen Kinnock, Minister of State for Care